Speech-Language Pathologists' Clinical Knowledge and Training in End-of-Life Care

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ABSTRACT

Speech-language pathologists (SLPs) are medical professionals that treat clients from birth to death. End-of-life (EOL) care encompasses a variety of aspects which requires a change in mindset for the rehabilitative and medical field. This study explored the various educational experiences, perceived competence, and knowledge of SLPs in EOL care. Survey research was implemented to gain insight into the current training methods, perceived competency levels, and overall knowledge of SLPs in EOL care. This research adds to the growing body of literature that supports the need for specific training and competence in the various multifactorial areas of EOL in efforts to increase the quality and quantity of speech-language pathology services to those at EOL and to promote patient outcomes, caregiver satisfaction, and overall quality of life.

Keywords: speech-language pathologist training, end-of-life, death/dying

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DEDICATION

This dissertation is dedicated to Cristian Candea and to all those who provide care during difficult times.

Chapter I

INTRODUCTION

Death is defined as the termination of all aspects that support life (Institute of Medicine (IOM), 2015). End-of-life (EOL) services refers to the care and support provided to an individual who has a life expectancy of less than six months (National Institute on Ageing, n.d.). According to the IOM (2015), Kubler-Ross increased awareness of death, grief, and loss with the development of her theory regarding the various stages surrounding grief and loss. This new concept acknowledged the variety of psychosocial aspects surrounding death and enhanced the care provided by health care professionals (IOM, 2015). Speech-language pathologists (SLPs) have a unique set of skills that would greatly benefit patients and their caregivers during EOL but are ill prepared for this task. Clinicians need to solidify their knowledge of the physical, cognitive, spiritual, and emotional changes that patients experience during the dying process and further develop their skills in care provision to the dying and emotional support to the bereaved (Chahda, Mathisen, & Carey et al., 2016; Javier & Montagnini, 2011; Noble et al., 2018; Pascoe, Breen & Cocks, 2018; Pollens, 2004; Pollens, 2012; Sharp & Shega, 2009; Waldron et al., 2010).

The objective of EOL care differs from the traditional view of rehabilitative care. The aim is not to restore functioning; rather, it is to enhance and maintain functioning over the remaining time the individual has left in accordance with the patient's goals. Due to the intricacies of EOL care, specific and formal training for SLPs is imperative to improve clinical competence and expertise. A proper foundation in EOL care will lead to increased competency for service provision that will enhance patient and caregiver satisfaction and comfort (IOM, 2015).

There is a need for a reframing in mindset to what is currently being taught in the academic curriculum (Chahda et al., 2016; Pollens, 2012). Research has demonstrated that SLPs are underutilized in aspects relating to EOL (Brighton et al., 2019; Chahda et al., 2016; Kelly, 2018; Mathisen, 2015; Noble et al., 2018; O'Reilly & Walshe, 2015; IOM, 2015). The misconceptions regarding restoration and SLPs, stigma surrounding death, lack of education and training in EOL care, and the complexities of EOL care perpetuates reduced referrals, and underutilization of the SLP.

Most current investigations relating to EOL care and the SLP utilize anecdotal evidence, use small samples, and demonstrate overall reduced quality of evidence. There is a documented need for further investigation to develop educational protocols for SLPs to ensure appropriate awareness of tasks, ethical and legal matters, and responsibilities when working with patients receiving EOL care. Due to the lack of investigation on EOL training, further research is warranted on the current methods of academic, clinical, and psychosocial training in the area of EOL for SLPs. This study will add to the body of literature by documenting SLPs' training methods, knowledge base, and perceived competency relating to EOL services.

Chapter II

LITERATURE REVIEW

EOL Care

There is a lack of standardization ~~with~~in terminology as it relates to EOL care. For the purpose of this dissertation, the definition of EOL services was framed according to the World Health Organization (WHO).

> The WHO defines EOL services as care that focuses on improving:
>
> quality of life of patients and their families facing the problem associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. (Chahda et al., 2016, p. 58-59)

Clinicians who provide competent EOL services will allow patients to have a dignified quality of life, maintain individuality, and freedom to make choices for as much time as achievable (Chahda et al., 2016). Increased recognition in the specialized area of EOL care has led to research interests in the development of protocols/guidelines, establishment of organizations, and creation of texts regarding EOL care. Recent studies highlight there is still a need for investigation into this dynamic, culturally based service.

The increase in research has led to the recognition that there is a need for specialized skill and the importance of SLPs on the interdisciplinary EOL care team.

Interdisciplinary care team. The IOM (2015) indicates that EOL care is best provided via an interdisciplinary care team. The current trend in research relating to EOL care and the field of speech-language pathology has validated that SLPs are a vital component of the interdisciplinary care team. Recent literature has demonstrated an increased recognition in the distinct, significant, and essential role that SLPs play in EOL care (Chahda et al., 2016; Pollens, 2012).

Meeting the unique and complex needs of the patient at EOL requires an interdisciplinary team approach (Chahda et al., 2016; Javier & Montagnini, 2011; Noble et al., 2018; Pascoe et al., 2018; Pollens, 2004; Pollens, 2012; Waldron et al., 2010). An interdisciplinary care team consists of a variety of medical professionals that focus on preserving the individual's dignity as they reach the end stages of life. Research has established that SLPs have a meaningful role in the care of those receiving EOL services (American Speech-Language Hearing Association [ASHA], n.d.c, Chahda et al., 2016; Pollens, 2012; Williams & Harvey, 2013). However, recent research indicates that SLPs, as medical professionals, often do not feel adequately prepared for their role in EOL care.

Within the SLPs' scope of practice, the definition and clarification of an SLP's role in EOL care has garnered some attention; however, the emphasis on educational training and establishing competencies are not well developed (Chahda et al., 2016). Strategic curricular instruction in EOL care should include topics of training in death, the dying process, psychosocial impact, and the cultural influences surrounding death (i.e., religion/spirituality, customs, beliefs, norms, and family support).

SLPs are essential members of the interdisciplinary care team as SLPs provide a unique set of skills to be offered to the individual receiving EOL care. For example, one functional area that deteriorates towards EOL is the ability to eat and drink safely. Swallowing management and treatment is within the scope of practice of a SLP. Interprofessional collaboration with a SLP could allow for maximum oral eating benefits, reduced alterations to consistencies, communication regarding cultural preferences, caregiver support and training, and ensuring that food/liquid consumption continues to be an enjoyable and safe experience (Chahda et al., 2016; Sharp & Shega, 2009).

The SLP's scope of practice benefits the patient receiving EOL care services in areas of communication, cognition, and swallowing/feeding abilities. Yet, there is lack of EOL care in the curriculum for this growing area of practice. The current SLP student lacks the appropriate training in the various aspects of EOL care which puts the future clinician and their future patients at a disadvantage. SLPs are ill-prepared for their role in EOL care. Future research needs to disseminate the best practices for training SLP students to identify and implement their role in the interdisciplinary EOL care team.

The role that SLPs play in EOL care and the rationale supporting the incorporation of an SLP in EOL services is well established; yet there is a lack of how SLPs are trained, what educational aspects relating to EOL are provided, and how competent current SLPs are able to provide services to patients at EOL. There are few studies that focus on SLPs training with EOL services. Due to the lack of research of SLP training in EOL care, a review of related disciplines such as occupational therapy and nursing was completed (Brazil, Kaasalainen, McAiney, Brink, & Kelly, 2012, Dimoula et al., 2019; Dunn, Otten, & Stephens, 2005; Meredith, 2010; Minosso, Martin, & Oliveria,

2017; Ross, McDonald, & McGuinness, 1996; Schnell-Hoehn, Estrella-Holder, & Avery, 2017). Research regarding clinical preparation in EOL care is sparse (Chahda et al., 2016; Dimola et al., 2019; Kelly et al., 2016; Kelly et al., 2018).

SLPs role in EOL. It is widely acknowledged in the literature that SLPs can help increase speech, language, swallowing, cognitive, and communicative abilities of those receiving EOL services. Research has indicated that SLPs are aware that they have a role in EOL care but do not feel confident, comfortable, or competent employing services to those at EOL. EOL care is a specialized area that is rarely covered in graduate curriculum. There is sparse research in EOL training provided to SLPs (Kelly et al., 2016; O'Reilly & Walshe, 2015).

Inclusion of the SLP in EOL care offers a variety of benefits to the patient, caregiver, and interdisciplinary care team. SLPs are specifically trained within techniques and teachings to improve cognitive-linguistic, swallowing abilities, and overall communicative abilities, but there is lack of training in how to manage care for those at the end stages of life (Pollens, 2012). To enhance communication, SLPs can assist those who are nonverbal with augmentative and alternative communication (AAC) and maintain communication to those with progressive illnesses. There is little investigation in EOL care with pediatric patients and those who require AAC (Costello, 2009).

Further, there is some research regarding the perceptions of EOL and feeding tube placement within those with advanced stages of illnesses (Pascoe et al., 2018; Sharp & Shega, 2009). Sharp and Shega (2009) found in their survey that it is essential to link theory and practice for effective training and discourse relating to EOL services. The

authors reported that there are various perceptions relating to advanced directives, counseling, alternative nutrition, diversity, and social issues relating to EOL. Ensuring effective diet consistencies, alongside treatment, and education to address the safe consumption of foods and liquids is within the scope of practice of the SLP and is a necessary aspect of those receiving EOL services (ASHA, n.d.c, Chadha et al., 2016, Pascoe et al., 2018; Sharp & Shega, 2009).

Pollens (2012) indicated that there is a considerable amount of education that SLPs need to ensure effective speech therapy services are delivered at EOL. Due to the special needs of an individual and their caregivers at EOL, there is a specific need for education and training. It is imperative that techniques for swallowing management, communication, and cognitive-linguistic abilities mirror the objectives of EOL care which is to enhance dignity, independence, education, and quality of life.

According to O'Reilly and Walshe (2015), SLPs feel they have an important role in EOL care. However, SLPs perceive that they are inadequately prepared to provide EOL care. The lack of research in this area warrants a significant need for continued investigation in preparing the SLP to provide EOL care. Review of the literature also found limited research relating to training/preparation for EOL services in adult and pediatric populations (Brighton et al., 2019; Chahda et al., 2016; Mathisen et al., 2015; Noble et al., 2018; O'Reilly & Walshe, 2015; Pascoe et al., 2018; Pollens, 2004; Pollens, 2012; Pfister, 2013; Waldron et al., 2010).

Repercussions of limited training and clinical expectations also affects graduate student training in the field. Regarding student perceptions, Rivers, Perkins, and Carson (2009) found that students were ill equipped to process and treat those who were

receiving EOL services. The authors noted that the students recognized the importance of their role in EOL care but did not feel as if they received adequate preparation. As a result, the students explicitly requested further academic and practical training in EOL care leading to the recommendation that strategic training in EOL care include psychosocial components, scope of practice, interprofessional training, and management strategies be offered in academic programs and job sites.

Current literature denotes that SLPs play a large role in the management of communication and swallowing of those receiving EOL services but there is a decreased amount of investigation on how SLPs gain the training and knowledge to effectively treat those who are at their final stage of life. Better prepared SLPs will be better equipped to advocate and educate other professions in their role in EOL care.

A variety of possible reasons for a lack of investigation into SLPs in EOL care could include type of patient diagnosis, SLPs viewed only as rehabilitative clinicians, reluctance to disrupt the bereavement process, and the stigma associated with death and dying (Pollens, 2004). In addition, while a role in the interdisciplinary EOL care team has been consistently established, other professionals often do not consider SLPs as a part of the interprofessional care team, which results in less referrals for clinical services (Chahda et al., 2016). The misconception that SLPs' roles do not expand past restoration has resulted in reduced speech therapy services amongst those receiving EOL care. Conflicting viewpoints relating to the use of SLPs in EOL care can result in underutilization of SLP services and limited training. This is especially concerning when a significant number of patients in EOL care have co-occurring disorders in cognitive-communication and swallowing (O'Reilly & Walshe, 2015; Salt & Robertson, 1998).

Further, research is largely focused on the best clinical practices in restorative care (Bentley & O'Connor, 2016; Brighton et al., 2019; Chahda et al., 2016; Eckman & Roe, 2005; Kelly et al., 2016; Kelly et al., 2018; Mathisen et al., 2015; Noble et al., 2018; O'Reilly & Walshe, 2015; Pascoe et al., 2018; Pfister et al., 2013; Pollens, 2004; Pollens, 2012; Salt & Robertson, 1998; Waldron et al., 2010).

Cultural Aspects of Dying

Culture influences the awareness, views, opinions on death, and medical involvement regarding the dying process (Mathisen et al., 2015; Toner & Shadden, 2012; Williams & Harvey, 2013). A person's culture is known to influence the type, amount, and intensity of medical care received (IOM, 2015). Some cultures engage in more cumulative decision making with their families than others. Autonomy, family influence, and preferences are shaped by the individual's culture. Research suggests that people who belong to a minority ethnic group may be "...less likely to use advanced directives or choose hospice care..." (IOM, 2015, p. 150). It is crucial that SLPs realize "...that in every culture, health, illness, death, caring, and healing are defined differently" (Toner & Shadden, 2012, p. 115). Values, beliefs, language, norms, symbols, and ideas are all shaped by culture. Toner and Shadden (2012) reported that "often, what physicians describe as poor compliance is simply a product of values and concerns that emerge from a culture that differs from that of the physician's" (p. 115). There are differences in culture relating to the intensity of treatment, where death occurs, and how interactions are exchanged between family and medical professionals. It is imperative that education not only be related to death and the dying process but also incorporate specific cultural aspects of the patient and caregivers. SLPs have the specific skill set to initiate

conversations relating to the desires of patient and caregivers with EOL care decision-making (Mathisen et al., 2015; Williams & Harvey, 2013).

Religion and spirituality. Religion and spirituality align with cultural diversity. According to Pecorino (n.d.), "religion is the most comprehensive and intensive manner of valuing known to human beings" (para. 6). Due to the scope of practice of speech-language pathology, it is important that the SLP is competent, respectful, and acknowledges the cultural complexities relating to nutrition and religion and spirituality (Mathisen et al., 2015). For example, religion and spirituality is often tied to eating, food choices, and fasting. Foods/liquids can represent a variety of spiritual and/or religious symbolism. In a variety of cultures, food is linked to caring for a person. Foods/liquids are often tied to traditions, customs, and beliefs.

Comprehensive evaluation and treatment are supported by the incorporation of the whole person (Mathisen et al., 2015). There is increasing investigation in the medical community into religion and spirituality but scarce research relating to the field of speech-language pathology (Mathisen et al., 2015). The IOM (2015) indicates that spiritual beliefs impact advanced care planning. There is a correlation between those with strong spiritual beliefs and the desire to employ life sustaining treatment measures due to hope of a miracle (IOM, 2015).

In related clinical fields, research in this area has resulted in the development of assessment measures that allow for tactful, compassionate, and an empathetic view of the person as a whole. There are federal mandates that require healthcare facilities "... to accommodate all patients' religious and spiritual needs" (Joint Commission, 2008; Mathisen et al., 2015). Yet, the field of speech-language pathology lacks the education,

assessment measures, interviewing skills, and techniques to appropriately identify, recognize, and respect the diverse cultural aspects of this area.

A literature review completed by Mathisen et al. (2015) found that there is a need for cultural competence related to spirituality in the field of speech-language pathology. There are a growing number of medical reviews that denote the importance of spirituality in healthcare but there is a gap when it comes to SLPs and spirituality. It is important to incorporate the patient's spirituality during evaluation and subsequent treatment. Recognition of spirituality as it influences care, as a way of managing loss, and as a calming source is important. Research suggests that terminally ill patients who have their spirituality/faith respected have better quality of life, healing, and recovery.

Psychosocial factors. There are a variety of psychosocial factors related to dying and caring for someone near the end of their life. Clinicians working directly with dying patients are forced to consider their own mortality. Competence in providing care to terminally ill patients is complex because the clinician must first evaluate their own feelings and beliefs surrounding death and grief and then develop an awareness of how their personal attitudes may color their interactions with patients and their caregivers.

The IOM (2015) stressed the importance of health care professionals' awareness of the variety of psychosocial factors that may influence preferences surrounding death. Communication with patients should be "unhurried, culturally appropriate, free of confusing medical terms and concepts, and adequately understood by the patient and the family" (IOM, 2015, p. 155). Increased encounters with those at EOL result in increased confidence in the practitioner. Increased proficiency and exposure to patients receiving EOL care resulted in better care for the individual. There is significant importance to

courses relating to EOL care for medical students but there is an emphasis that clinical rotations and face-to-face experience results in increased applied realistic familiarity and expertise (Dunn et al., 2005).

Brighton et al. (2019) found through qualitative research that there is not only grief with the caregivers and patients but with the therapist as well. Clinicians may experience high levels of stress and anxiety due to witnessing prolonged suffering. Specific training and acknowledgement of the bereavement process for healthcare professionals is imperative (Brighton et al., 2019). Toner and Shadden (2012) indicated that the SLPs' rationale for being in the profession is "making a difference in someone's life" (p. 111). Yet, there is an increased feeling of stress syndrome in the SLP when loss of a patient occurs. Evidence suggests that increased experience, exposure, and training in EOL reduces overall stress (Toner & Shadden, 2012).

Counseling. Counseling is an important aspect in the field of speech-language pathology. "Counseling is a broad term that refers to assistance provided in an interactive manner to individuals (i.e., clients, patients, and/or students) and their families/caregivers dealing with challenging emotions and life situations to facilitate realistic and clearly understood goals and improve quality of life (ASHA, n.d.b, para. 1). It is the medical responsibility and clinical duty of the SLP to provide culturally competent counseling. Roe and Leslie (2010) indicated that bonds are created between therapist and patient. This connection can be different when EOL care is being provided or initiated (Roe & Leslie, 2010).

Spillers (2007) provided an outline for SLPs working with individuals receiving EOL care and recommended that SLPs gain understanding of the different patterns and

types of grief, mourning, and mortality. Counseling is a distinct area of practice, especially regarding death and grief with patients who are receiving EOL care and is not consistently discussed within graduate curriculums and clinical practicums. Introduction of different prototypes, demonstrations, and discussions will reduce the stigma associated with death and dying, improve empathy, and enhance care provided by SLPs (Spillers, 2007).

Consistent and ongoing education to the caregivers about the normal dying process is important to minimize feelings of guilt and prepare them for the patient's death. Caregivers are the first to recognize when the patient's intake begins to decrease. Caregivers may become frightened and may explore options of artificial nutrition (Bentley & O'Connor, 2016; Spillers, 2007; Pollens, 2012). The SLP is the expert who can explain the process surrounding feeding in common language.

Bentley and O'Connor (2016) found that caregivers often have difficulties accessing EOL care. The authors found that caregivers feel that EOL care is lacking in themes of gaining education, appropriate assistance, and being ready for the death of their loved one. Appropriate education, referral of needed services, and counseling is required to ensure caregivers and the patient are receiving the best services. Information relating to expectancies, probabilities, and education to caregivers and the patient is required to ensure quality care and reduce difficulties during the EOL experience (Bentley & O'Connor, 2016).

Addressing EOL in Education

There has been recent attention on the importance of professional cooperation in healthcare. Communication and collaboration between professions is especially important

when providing services to patients receiving EOL care. Research has demonstrated that curriculum regarding EOL care should involve collaboration between professionals during training and enhance principles of trust, fairness, ethical treatment, reliability, integrity, and admiration for others.

While there are a variety of recommendations on how to educationally prepare future clinicians, research indicates there is a lack of explicit teaching in EOL care for medical professionals. Often, learning of EOL care for students in medical professions is causal and unofficial. The rationale behind this misconception may be attributed to the ideas of "death is a medical failure" and there is no reason to assign students to dying patients because there is "nothing to learn" from them (IOM, 2015, p. 63). Yet, studies have shown that the incorporation of EOL care to the curriculum has demonstrated improved clinical abilities and reduced anxiety amongst students (Von Gunten et al., 2012).

According to the IOM (2015), it is imperative that students are provided education to improve resiliency, acceptance of the variability of the course of the disease, responsiveness, and the difference in the goals established for the patient. EOL services require distinct training and education focusing on quality of life. Noble et al. (2018) incorporated medical recommendations and parameters for allied health professionals when providing EOL care. Noble et al. (2018) created and implemented "Clinical Guidelines for Dying Patients (CgDp)". Participants of Noble's et al.'s (2018) study found their guidelines to be helpful but complicated.

A recent literature review by Kelly et al. (2016) found inadequate investigation in EOL care training in the field of speech-language pathology. Additional difficulties of

providing services to those who are dying included: reduced training, preparation, and knowledge of the SLP to work with those receiving EOL care were noted by the authors. Kelly et al. (2016) concluded that SLPs have a clear responsibility in providing counseling, caregiver training, swallowing, and cognitive-communicative management to those receiving EOL services. Eckman and Roe (2005) indicated that there is an increasing need in EOL services for SLPs but that further information, education, training, and investigation is required to better SLPs competency in this area.

Mathisen et al. (2011) detailed the incorporation of EOL training for speech-language pathology students over a four-year training process and found the training program to be vital to the students as they enter the workforce. An interdisciplinary program to train undergraduate SLP students in palliative care has demonstrated positive outcomes in improving the clinician's success in EOL care. Research has established the significance of EOL training in academic institutions. EOL services are often overlooked in academic institutions even though SLPs are universally utilized in EOL care. The authors documented that students found value in EOL care training (Mathisen et al., 2011).

Currently, academic curriculum and training for speech-language pathology centers on restorative and rehabilitative teachings. Chahda et al. (2016) indicated the importance of modifying the current teachings to address the specific needs of an individual receiving EOL services. Waldron et al. (2010) indicated that it is not just the field of speech-language pathology that has a deficiency in training in EOL care. Waldron et al. (2010) found that any related health profession that is generally viewed as offering restorative treatment is often overlooked in this distinct area.

Clinical and academic training. It is well established that healthcare professionals can greatly impact the quality of life of the patients they service, yet to ensure that competent methods of treatment are delivered, appropriate education must be provided. According to IOM (2015), there are a variety of aspects that apply to the clinical competency in EOL care. A solid foundation regarding best practices, interdisciplinary collaboration, counseling, and the many factors surrounding death needs to be incorporated in the education of healthcare professionals. However, specific training relating to EOL care is recommended but is often lacking direction, adequate curriculum, and appropriate clinical experiences (IOM, 2015).

Regarding the field of communication sciences and disorders, there is a significant absence (or at best inconsistent) instruction of EOL care (Chahda et al., 2016). SLPs involved in EOL care have primarily sought interprofessional education to provide foundational information and guidance. SLPs are involved in interprofessional communication, engaged in care plan and discharge meetings, help adequately support nutrition/hydration, and support the communication needs of those at EOL. Alternative instruction can include rehabilitation conferences, interprofessional support, and continuing education.

Pascoe et al. (2018) reported that SLPs have a role in treating patients at EOL; however, in their survey, the authors noted insufficient evidence on clinical instructional practices. An overwhelming 70% of the authors' participants indicated that there was limited and/or an absence of training in EOL care (Pascoe et al., 2018). Due to EOL being a multifaceted service, there should be more opportunities for EOL education. Further, Pascoe et al. (2018) noted that SLPs who received curricular instruction in EOL

care resulted in higher scores within clinical competencies. The authors found that hands-on activities with a strong educational basis alongside clinical placements with those receiving EOL care would improve preparedness, increase job satisfaction, and reduce stress.

There are several reasons that could account for the absence of education in EOL, which could include: curriculum concerns, reduced collaboration between professionals, complexity of EOL care, and reduced focus on effective means of communication (IOM, 2015). Another reason listed by the IOM (2015) is that there is reduced collaboration amongst disciplines, which results in narrowed views and the inability to effectively serve the patient. This reduced exposure and awareness of different discipline's scope of practice results in reduced knowledge on how to effectively complement one another. In general, the use of an interdisciplinary method is utilized to effectively treat those receiving EOL care. Incorporating interdisciplinary teachings in the curriculum may be beneficial to improving training and enhancing effective communication amongst disciplines. The IOM (2015) indicates that effective communication, is required by every practitioner involved in the interdisciplinary care team. Wright et al. (2008) established that practitioners are lacking in communication when discussing a terminal prognosis. The intricacies of EOL care involve a need for education within techniques to establish an effective dialogue. Yet, the area of training relating to teaching effective communication is lacking with only a few specialty fields in medicine who have begun teaching these skills.

Behavioral aspects of conveying information, providing instruction, support and education is a foundational basic competency for providing effective care.

Understanding of the behavioral aspects of communication is required to ensure competent caregiver support. However, the literature review yielded no training programs for SLPs to effectively communicate with those at EOL.

Measures to Assess Knowledge and Competence in EOL Care

In related clinical fields (e.g., nursing, occupational therapy, physician residents, etc.), researchers have focused efforts into developing validated instruments to gauge the various aspects surrounding practitioners' perceptions, competence, knowledge, and feelings concerning death and dying. Currently, a number of validated tests to assess the knowledge of health care professionals in EOL care are available (Brazil et al., 2012; Minosso et al., 2017; Pfister et al., 2013; Ross et al., 1996; Schnell-Hoen et al., 2012). However, there are no systematic and validated assessment tools that will assess SLPs' perceptions, knowledge, and competencies in EOL care. This is a significant concern considering this area is a clinical responsibility.

The Palliative Care Quiz for Nursing (PCQN) is a well-published tool that is often used in rehabilitative health research (Ross et al., 1996). The PCQN is an empirically studied assessment of EOL care designed for nurses but has been adapted in a variety of studies for other disciplines and a variety of languages (Ross et al., 1996). The PCQN is a free-to-use, standardized tool that can be used in the original form or with adaptations if appropriate citations are acknowledged (Eleke et al., 2020). The PCQN is a quick, validated assessment consisting of 20 statements in which respondents indicate true, false, or don't know regarding EOL content (Ross et al., 1996).

The PCQN is a validated evaluative measure that consists of 20 true or false questions targeting healthcare professionals' knowledge in three domains: philosophy and

principles, control of pain and other symptoms, and psychosocial aspects (Ross et al., 1996). See Appendix C for the original PCQN by Ross et al. (1996). A highlight of the PCQN is that it can quantify competency measures for healthcare professionals (Brazil et al., 2012; Minosso et al., 2017; Ross et al., 1996; Schnell-Hoehn et al., 2012). For example, Brazil et al. (2012) found that nurses self-reported high scores of EOL care knowledge, but their PCQN scores revealed low scores in EOL knowledge and competency.

In a similar study, Schnell-Hoehn et al. (2012) found that when giving the PCQN to nurses who serve in a cardiac unit, lack of training and knowledge in EOL care was evident. Incongruity between self-confidence and actual knowledge scores on the PCQN led Brazil et al. (2012) and Schnell-Hoen et al. (2012) to recommend increased training in EOL care for medical professionals.

Summary

It is imperative to provide educational opportunities to SLPs to ensure quality services are delivered to patients across the age span. The lack of research in the field of speech-language pathology coupled with clinical duty in providing quality EOL care demands further investigations into SLPs' clinical competency. This study will explore practicing SLPs' educational experiences with multicultural factors in clinical preparation and perceived confidence in providing EOL care. It was hypothesized that SLPs had limited experiences from graduate curriculum/practicum in this area. Due to the paucity of educational resources, it is hypothesized that SLPs would demonstrate low scores on a competency assessment tool. The questions of this study are:

Research Question 1: Do SLPs receive training in EOL care?

Research Question 2: Are SLPs trained in psychosocial aspects relating to EOL care?

Research Question 3: Do SLPs demonstrate competent knowledge in EOL care?

Research Question 4: How do SLPs perceive their competence in caring for those at EOL?

Research Question 5: Are there differences between SLPs' perceived competence and actual knowledge in EOL care?

Chapter III

METHODOLOGY

The purpose of this chapter is to introduce the research methodology for this quantitative study regarding the current methods of training in EOL care the SLP receives. The Institutional Review Board (IRB) at Valdosta State University granted approval for both the pilot study and subsequent dissertation study (Protocol Number: 04060-2020) (see Appendix E). This chapter is organized by explaining the methodology of both the pilot and the dissertation study.

Study Design

A non-experimental survey was selected as the design for this investigation. A non-experimental survey is considered descriptive research methodology which permits the investigator to study and illustrate current circumstances (O'Reilly & Walshe, 2015). This method of research compiles knowledge, attitudes, and beliefs from a variety of individuals (O'Reilly & Walshe, 2015). Inclusion criteria included any speech-language pathologist who had graduated with their master's degree. Those in their clinical fellowship year could complete the survey. There were no exclusion criteria.

Rationale for methodology. Survey research was utilized to investigate the current competence, training, and knowledge of the SLP in the distinct and complex area of EOL. Survey research was deemed as the most effective and logistically sound means of collecting data to appropriately answer the research questions. Survey research was also warranted due to the Coronavirus disease 2019 (COVID-19) pandemic, limited access to potential participants, and reduced investigation into this area. This method of

research adheres to the necessary safety protocols of the Centers for Disease Control and Prevention (CDC), (n.d.). Further, a literature review highlighted that data collection via survey was an appropriate method to investigate EOL care in the field of speech-language pathology.

Pilot Study

The dissertation committee recommended a pilot study to gauge the feasibility and ascertain the prevalence of EOL care as a topic. The IRB at Valdosta State University granted approval on August 03, 2020 (see Appendix E). The survey and data collection for the pilot study was generated using Qualtrics software (Qualtrics, 2020). The pilot survey was opened on August 03, 2020 and ceased data collection on August 07, 2020.

Data collection instrument. To devise the survey instrument, a literature review was completed to ascertain various research relating to the training of SLPs for EOL care. Survey questions were adapted from various studies pertaining to EOL care that included demographics, cultural aspects of EOL, and EOL training (Minosso et al., 2017; O'Reilly & Walshe, 2015; Rivers et al., 2009; Ross et al. 1996). The information from the literature review was united with the investigator's academic and clinic knowledge relating to EOL services to enhance survey validity (O'Reilly & Walshe, 2015). The survey sought to gain information related to the respondent's knowledge, current training, and the multicultural competency pertaining to EOL. The pilot study survey consisted of 33 non-randomized multiple-choice questions (see Appendix A for the pilot study survey). There was no time limit survey completion. Only the surveys that were completed in their entirety (31 responses) were analyzed. These surveys received from

the pilot study were not used in the overall data analysis for the larger study. Data were collected via the survey instrument within the areas of demographics, EOL training, and the adapted PCQN. The data interpreted from this pilot study were used to adapt the content of the dissertation survey and correct errors. Qualtrics was utilized as the platform for survey construction and facilitation (see Appendix A for the survey used for the pilot study). The data collection instrument was constructed so that all questions were not randomized to maintain the power of consistency and continuity. The survey instrument was designed to evaluate demographic information, EOL training, and knowledge of EOL. The demographics portion included questions to better understand demographic information relating to the respondents. EOL training was investigated with questions relating to perceived knowledge regarding EOL care, where EOL education took place, and aspects of training received. Knowledge of EOL care was assessed with an adapted PCQN. The PCQN was utilized as the method of determining knowledge in the respondents as it is a validated assessment tool and there is currently no instrument available specific to SLPs

Pilot study participants. The respondent goal for the pilot study was to recruit 20 participants who self-identified as SLPs. The survey was open for four days and achieved 39 responses. Participants for the pilot study were SLPs gained via snowball sampling. An anonymous survey link was provided via email to different facility facilitators and posted on social media platforms.

The participants all identified as females (100%). The participants indicated the following ethnicities 35.48% of the participants identified as White or Caucasian, 3.22%

identified as Hispanic or Latino, 58.06% identified as Black or African American, and 3.22% identified as Asian or Pacific Islander.

Most of the participants graduated from more recent years 2008-2013 (32.25%) and 2014-2020 (25.80%). Most training in EOL was received through on the job training (32.69%). Well over half of the participants (61.29%) did not receive any classes in EOL care in their graduate curriculum. See Table 1 for more information.

Table 1. *Pilot study graduation year, education/training received, and coursework*

Graduation year (n=31)	
1977 or before	2 (6.45%)
1978-1983	1 (3.22%)
1984-1989	1 (3.22%)
1990-1995	2 (6.45%)
1996-2001	2 (6.45%)
2002-2007	5 (16.12%)
2008-2013	10 (32.25%)
2014-2020	8 (25.80%)
Type of education/training received in EOL care (n=52)	
Undergraduate training	3 (5.76%)
Graduate training	9 (4.68%)
Seminar/Conference	6 (3.12%)
Continuing Education Course	11 (5.72%)
On the job training	17 (32.69%)
No training	6 (3.12%)

Graduate Coursework (n=31)	
Enrolled in end-of-life course	0 (0%)
End-of-life was embedded in courses	12 (38.70%)
No classes in end-of-life in the graduate curriculum	19 (61.29%)

Pilot study data results. The majority of the participants 41.93% of the participants reported that they were moderately knowledgeable, 32.25% of participants reported that they were not knowledgeable, and 25.80% reported that they were knowledgeable in aspects of EOL care.

The majority of participants (77.49%) indicated that they did not receive adequate training in the physical aspects of the dying process, 70.96% of participants reported that they did not receive adequate training in the psychosocial aspects of the dying process, and 70.96% of participants reported that they have not received adequate training in cultural aspects of the dying process. The majority of the 74.19% of participants reported they did not receive adequate training in the spiritual aspects of the dying process, and 54.83% of participants reported that they received adequate training in the ethical considerations surrounding EOL care.

The results of the pilot study indicated that further investigation is needed in EOL care training specifically relating to knowledge and competency within this distinct population. Results found that 14.06% participants received no training in EOL care. Three of the 31 participants (9.67%) demonstrated adequate knowledge per the PCQN. These three participants graduated in the years of 1977 or before, 1990-1995, and 2002-2007. Pilot study results revealed on the job and continuing education courses were the

highest for how the participants received training in EOL care. The participants of the pilot study were most successful in the psychosocial aspects on the PCQN, followed by control of pain and other symptoms, and lastly, philosophy and principles. The very low passing rate on the pilot adapted PCQN section highlighted the urgent need to further research this topic and the implications in clinical practice.

Dissertation Study

The data achieved from the analysis of the pilot study helped revise and improve the dissertation survey (see Appendix B for Dissertation Survey). These modifications were subsequently approved by the IRB at Valdosta State University (see Appendix D for the implemented changes in the survey instrument). The platform of Qualtrics (2020) was utilized for the dissertation study. The goal was to ensure a representative sample of the larger population. The objective was to gain 384 respondents over the course of September 04, 2020 to September 25, 2020. The targeted number of the sample size was determined via the Qualtrics (2020) Sample Size calculator. The perimeters for determining the sample size were as follows: 95% confidence level, population size was gained from ASHA (2020) from the Profile of ASHA Members and Affiliates Report, which was 181,628, and margin of error was 5%, which led to an ideal sample size of 384. However, only 207 participants were recruited.

Dissertation study participants. Participants recruited for this study were SLPs that were gained by means of provision of an anonymous survey link on the discussion boards of ASHA's (n.d.a) Special Interest Groups (SIGs). SIGs are defined by ASHA (n.d.a) as a method "... to promote specific professional interests among members, develop communication and networking in diverse professional settings, identify and

convey concerns and needs to the Association's governance, and assist in policy formation" (para. 1). The survey was distributed to four SIG platforms-Gerontology (SIG 15), Neurogenic Communication Disorders (SIG 2), Swallowing and Swallowing Disorders (Dysphagia (SIG 13), and Administration and Supervision (SIG 11). Between September 04, 2020 and September 25, 2020, 249 participants began the survey; however, only 207 surveys were completed and utilized in the data analysis.

Participant characteristics. A total of 249 participants initiated the survey, 207 surveys were completed in their entirety. Only the completed (207) surveys were used for analysis. Due to the methodology, an overall response rate was unable to be determined. Participants of this study identified themselves as primarily female (94.20%) and White or Caucasian (91.78%). The largest number of participants graduated from 2008-2013 (23.56%). Over half of the participants worked in a hospital (53.51%), no participants worked in a school alone. Most participants (90.33%) reported that they have the potential of providing therapy to an individual receiving EOL services (see Table 2 for more information).

Table 2. *Dissertation study graduation year, education/training received, and coursework*

Graduation year (*n*=207)	
1977 or before	5 (2.40%)
1978-1983	17 (8.17%)
1984-1989	26 (12.50%)
1990-1995	26 (12.50%)
1996-2001	24 (11.54%)
2002-2007	33 (15.87%)
2008-2013	49 (23.56%)
2014-2020	27 (12.98%)
Type of education/training received in EOL care (*n*=403)	
Undergraduate training	7 (1.73%)
Graduate training	27 (6.68%)
Seminar/Conference	64 (15.84%)
Continuing Education Course	122 (30.20%)
On the job training	157 (38.95%)
No training	26 (6.44%)
Graduate coursework (*n*=209)	
Enrolled in end-of-life course	8 (3.81%)
End-of-life was embedded in courses	33 (15.71%)

No classes in end-of-life in the graduate curriculum	168 (80.38%)

Table 3. *Participants' work setting*

Setting (*n*=207)	
School	4 (1.48%)
Hospital	145 (53.51%)
Skilled Nursing Facility	55 (20.30%)
Home Health	22 (8.12%)
Telepractice	6 (2.21%)
Other	38 (18.35%)
Other setting (*n*=38)	
Senior Care Rehab. Administration	1 (2.63%)
Subacute	1 (2.63%)
Outpatient Clinic	8 (21.05%)
Assisted Living Facility	1 (2.63%)
University	11 (28.94%)
Private Practice	4 (10.52%)
Day Habilitation/Outpatient Voice Clinic	1 (2.63%)
Long Term Residential Facility	2 (5.26%)
Private ENT Office	1 (2.63%)
Mobile MBSS	1 (2.63%)
LTACH	1 (2.63%)
Unemployed	1 (2.63%)
Outpatient House Calls/Assisted	1 (2.63%)

Living/Memory Care	
Outpatient/Assisted living facility	1 (2.63%)
Outpatient Hospital	1 (2.63%)
Not specified	2 (5.26%)

Dissertation Study Measures

Prior to accessing the survey, the participant was asked to provide consent by moving forward on the survey (see consent form in Appendix F). The survey was anonymous and collected no identifying information. The survey addressed possible duplications by allowing only one respondent with the same IP address to access the survey once. No IP addresses were retained to ensure anonymous responses.

Deletion of survey questions regarding type of employment and state in which the participant received their education were removed. The question regarding "what year did you graduate" was modified to increase the specificity of the question to- "what year did you graduate with your master's degree?" The survey was also modified by adding two questions- what setting the participant worked in and a yes/no question regarding the potential of providing therapy to an individual receiving end-of-life services. For the end-of-life training section of the survey, the word adequate was replaced with competent for training questions. Two misspellings were corrected in the adapted PCQN (i.e., page-pain, regime-regimen). For the adapted PCQN, the option of unsure was added to true and false responses. This will be beneficial due to the format of the PCQN being true or false, leading to a potential high rate of guessing correctly. If the participant chose unsure, the question was scored as wrong. See Appendix D for the adapted PCQN.

Reliability measures. The investigator used a form of intra rater reliability to recode a portion of the data from Qualtrics. Using a visual inspection strategy, 42 participants (~20%) were randomly chosen to review coding data. Of that ~20%, one error was found regarding the total number of participants passing the PCQN which equaled 41 out 42 data entries were correct (97.61%). The coding error was corrected in the data set.

Chapter IV

RESULTS

This chapter will present the results by research question. The research questions investigated by this study were:

Research Question 1: Do SLPs receive training in EOL care?

Research Question 2: Are SLPs trained in psychosocial aspects relating to EOL care?

Research Question 3: Do SLPs demonstrate competent knowledge in EOL care?

Research Question 4: How do SLPs perceive their competence in caring for those at EOL?

Research Question 5: Are there differences between SLPs' perceived competence and actual knowledge in EOL care?

Research Question 1: Do SLPs receive training in EOL care?

Type of training and education into the complex area of EOL was a major focus of this study. The most common training method for EOL was on the job training (38.95%), followed by continuing education course (30.20%). Academic training (undergraduate and graduate) together counted for less than 10% of the training in EOL (8.43%). A small number of participants (6.44%) indicated that they have received no training in EOL at all. Most participants (97.10%) reported that they did not receive

competent training in the dying process and 83.57% of participants reported that they did not receive training in the ethical considerations surrounding end-of-life care.

Research Question 2: Are SLPs trained in psychosocial aspects relating to EOL care?

The majority of participants (92.27%) indicated that they have not received competent training in the psychosocial aspects related to the dying process. Most participants (95.65%) reported that they have not received competent training in the cultural aspects of the dying process. The majority of participants (96.61%) stated they had not received competent training in the spiritual aspects of the dying process.

Research Question 3: Do SLPs demonstrate competent knowledge in EOL care?

Participants' knowledge was evaluated with the adapted PCQN. Achievement of 15 is sufficient knowledge on this assessment. Only 17 (8.21%) participants achieved greater than 15 on the PCQN. Participants demonstrated the most success on questions relating to philosophy and principles, followed by psychosocial aspects, and finally control of pain and other symptoms. There were only three questions on the PCQN in which over 80% of the participants were successful- "palliative care is only appropriate in situations where there is evidence of a downhill trajectory or deterioration", "the provision of palliative care requires emotional detachment" and "suffering and physical pain are synonymous"

Research Question 4: How do SLPs perceive their competence in caring for those at EOL?

Participants were asked to judge their own knowledge regarding death and dying. Over half of the participants (61.35%) perceived themselves as moderately

knowledgeable, while 31.88% perceived themselves as knowledgeable in death and dying and 6.76% of participants reported that they were not knowledgeable.

Research Question 5: Are there differences between SLPs' perceived competence and actual knowledge in EOL care?

The majority (93.23%) of participants indicated they were either moderately knowledgeable or knowledgeable in death and dying. However, only 17 (8.21%) participants passed the PCQN with a score of 15 or greater which is characterized as sufficient knowledge on the tool. All participants (100%) who passed the adapted PCQN (achieved a score of 15 or greater) were female. Over half (68.75%) of the participants indicated that they were knowledgeable in EOL care. Most participants (87.5%) who passed worked in a hospital setting.

Of the 17 participants who achieved a score of 15 or greater on the adapted PCQN, 23.53% graduated between 1996-2001. The graduation years of 1984-1989 was the second highest (17.64%) for those who passed the PCQN. All participants received training in EOL via a continuing education course. The majority (88.23%) of the participants of the successful participants on the adapted PCQN received on the job training in EOL.

The average score on the PCQN was 10.09. This is significantly lower than a score that translates to appropriate knowledge in EOL care (Ross et al., 1996). No participant received a score of 20 on the PCQN. The highest score achieved was 18 and the lowest was 1. The mode scores were 9 and 11.

Analysis

Data were analyzed by means of descriptive statistics to analyze current knowledge, perceptions, and training of EOL in SLPs. Statistical analysis tools within Qualtrics (Qualtrics, 2020) and Excel (Microsoft Corporation, 2019) were utilized to analyze and review collected data. Only surveys that were entirely completed were analyzed. Analysis of data involved incorporation of descriptive statistics to delineate the participants' perceptions, knowledge, and demographic information. For questions 1-5 in the demographics section and 1-8 in the end-of-life training section, means, medians and standard deviations were completed to understand the respondents training in EOL care. Text answers written into the "other" category for question four in the demographic setting- "what setting do you work in" were quantitatively and qualitatively analyzed. Further analysis was completed to determine whether the perceived competence levels matched the level of knowledge on the PCQN as well as what year of graduation corresponded with competence on the PCQN. It was thought that the more recent graduates would present with higher levels of knowledge than the older graduates as the evolving curriculum accounting for additional psychosocial aspects. Results of the study found the participants identified as White/Caucasian females who generally did not receive academic training in EOL in graduate school; rather, participants received the most education via on the job training with the second highest nomination for education being continuing education courses. Due to the participants limited education and training in EOL care, 91.79% did not pass competency on the PCQN; however, these are participants who identified as currently having or have the potential of having a patient at EOL. Further, participants' responses indicated a lack of training in five specific content areas (i.e., spirituality, ethical considerations, psychosocial, physical aspects, and cultural

considerations) relating to death and the dying process. This is especially concerning as the 17 participants who did pass competency on the PCQN did not feel as though they competently trained in graduate school in all five cultural areas. SLPs must adhere to the code of ethics. As a part of the SLP's code of ethics, increasing cultural knowledge and cultural humility is an ethical standard for SLPs which is not reflected in practice (ASHA, 2016).

Chapter V

CONCLUSION

Discussion

This study aimed to investigate the current training and knowledge regarding EOL care and the SLP. The intent of the study was to gain understanding of what aspects relating to EOL care are SLPs trained in and how/where they are trained. Data were collected on the current training methods that SLPs received to prepare for clinical interactions with patients in need of EOL services, their perceived knowledge levels, and their actual knowledge levels relating to EOL. Similar to previous studies (Meredith, 2010; Pascoe et al., 2018; Rivers et al., 2009), there is limited competent training and methods to prepare healthcare professionals to provide services to those at EOL. The majority (93.23%) of participants indicated that they felt they were moderately knowledgeable or knowledgeable in EOL, yet only 7.72% of participants were able to achieve a score correlating to sufficient knowledge on the adapted version of the PCQN. Participants scored highest on the domain of philosophy and principles, followed by psychosocial aspects, and control of pain and other symptoms. To highlight the participants' skewed perceptions of self-competency, 193 out of 207 participants rated

themselves as moderately knowledgeable to knowledgeable however only 8.21% passed the PCQN.

Clinical Implications

This study demonstrated that SLPs currently have a critical gap of knowledge in EOL care. There were no significant moderators determining knowledge levels in EOL care. The average score on the adapted PCQN being 10.09 demonstrates low overall levels in knowledge of EOL while a score of 15 or higher is passing. Possible reasons for low knowledge levels could be attributed to reduced training in curriculum, reduced offerings in EOL continuing education courses, and the continued misconception that SLPs only present a restorative role. It is well established that SLPs have a crucial role in EOL care, yet there is little investigation of how SLPs are appropriately trained to provide competent services in the distinct, diverse, and multifactorial area of practice. This study demonstrated concerns for clinical practice because 90.33% of participants reported that they have the potential of providing therapy to an individual receiving EOL services and only 8.21% demonstrated sufficient knowledge on the PCQN. This gap in education and training is especially concerning as it has effects on ethical and legal practices of current practicing SLPs.

Continued belief in common misconceptions relating to death and dying were noted in the participants. The majority of participants believed that burnout is inevitable when working with those at EOL, that with the use of morphine for pain management drug addiction is a major problem, and that EOL care philosophy is not compatible with that of aggressive treatment. These continued beliefs in common misconceptions highlight the importance of education and training in the area of EOL.

One of the assumptions was that psychosocial aspects of death/dying would be the area that participants would score highest upon due to the other areas-principles and philosophies and management of pain and other symptoms being areas not necessarily targeted in the academic curriculum. Participants in the dissertation sample scored higher on aspects of principles and philosophies on the adapted PCQN than the psychosocial domain. Another assumption was that participants from more recent years of graduation would have more success on the adapted knowledge assessment of the PCQN. Yet, the results demonstrated only one participant from recent years (2014-2020) was able to achieve a score corresponding to sufficient knowledge. This result may be due to on the job training and more work experience than newer graduates.

According to Kelly et al. (2018), "complex legal and ethical issues arise when working outside of a curative model" (p. 321). Interestingly, 83.57% of participants reported they received competent training in ethical considerations regarding EOL care. The breadth of ethical considerations relating to EOL is quite multifaceted and broad. Further research targeting what aspects are taught and where the training is taking place is important. Ethical considerations were what the participants reported to having highest levels of competent training. Aspects relating to spirituality (3.37%), cultural (4.33%) aspects, physical (2.88%) aspects and psychosocial (7.69%) aspects were significantly lower. The lack of appropriate knowledge and reduced training in this area highlights a need for further investigation and training in this area. The known role SLPs play in EOL but lack of appropriate knowledge results in ethical violations. These ethical violations can affect patient status, hasten death, lead to poor quality of life, reduction in

dignity, inability to effectively respect and communicate with various cultural influences with caregivers and patients and overall poor quality of care.

Limitations

There were a variety of limitations to this study. The original PCQN has an internal consistency below .70 and with the use of an adapted tool, there is a reduced statistical reliability in the use of this instrument (Ross et al., 1996). Further, this instrument was designed for the healthcare profession of nurses, not SLPs.

Limitations were also found in the methodology and design of the study. These limitations included availability and access to a computer, technology, and appropriate internet. Another limitation is that the study was completed during the comprehensive stress of a global health crisis. Attrition in surveys may have been caused by the workstyle transition to computer/video conferencing caused by the COVID-19 pandemic. Further, the investigator did not have an implemented plan to remind participants to complete active surveys. The area of EOL is also a difficult aspect to study. Kelly et al. (2018) indicated that research in EOL is difficult and often not "appropriate" or "possible" to utilize higher quality research levels (p. 321). The questions on the survey asked the participants to recall content provided from their academic curriculum. This may have resulted in inconsistency between what was provided and what was recalled. The sample size was small and non-representative of all SLPs. The choice of providing the survey to only four SIGs limited the participants who were available. The sample lacked heterogeneity, identifying predominantly female and as White/Caucasian. The survey question regarding perceived knowledge relating to EOL may have resulted in

confusion in the participants. The choice of "moderately knowledgeable" instead of "somewhat knowledgeable" may have led to inflated scores in this area.

Recommendations for Future Research

Significantly more research is required in EOL and the field of communication sciences and disorders. Future research should focus on development of a validated tool specific to SLPs to assess knowledge, clinical skills, and multicultural competencies related to EOL care. Research should include a review of the current coursework and aspects of EOL in the curriculum in various universities and colleges for EOL content, methods of determining competency, and feelings towards EOL. Perceptions of students, professors/lecturers, and current SLPs regarding EOL would be beneficial. Due to the high number of participants reporting on the job training as the method for EOL training, further investigation into who is providing the EOL training, the quantity, type, and quality of the on the job training specific to EOL care would be beneficial. Research regarding the amount and effectiveness, quality of education provided by seminars/conferences, and continuing education courses available to SLPs specific to EOL care would be beneficial to improving the care provided by SLPs to those at EOL.

Conclusion

SLPs play a crucial, and interprofessional, role in serving individuals and their families during EOL care. Yet, the training to prepare SLPs to effectively engage and execute these multifactorial parameters (e.g., spirituality, cultural awareness, psychosocial factors, pain management) are not established in the field of communication sciences and disorders. Aspects surrounding death and dying are not consistently part of the clinical training or educational curriculum, with most instruction occurring via on-

the-job training with limited, if any, oversight. This identified framework of scarce training paired with active clinical practice may result in significant ethical violations for SLPs which may result in neglect of the patient's cultural and personal rights to maintain dignity during EOL. Provision of services to patients at EOL requires a shift in the mindset of SLPs and organizational agencies to address the academic, clinical, and research needs of this culturally unique population.

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APPENDIX A:

Pilot Study Survey

End-Of-Life Survey

For the purpose of this survey end-of life-services and/or palliative care services are used synonymously in this survey and are defined as follows: "an approach that improves the quality of life of individuals and their families facing the problems associated with life threatening illness, through prevention and relief of suffering by means of early identification and impeccably assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (World Health Organization [WHO], 2020, para. 1).

A. Demographics

1. Please indicate your gender
Female
Male
Prefer not to say
Other:

2. Please specify your ethnicity
White or Caucasian
Hispanic or Latino
Black or African American
Native American or American Indian
Asian / Pacific Islander
Prefer not to say
Other:

3. What year did you graduate?
1977 or before
1978-1983
1984-1989
1990-1995
1996-2001
2002-2007
2008-2013
2014-2020

4. Please indicate your type of employment?
Part-time
Full time
Other:
5. What state did you receive your education? Drop down

B. End-of-Life Training

1. Rate your knowledge about death and the dying process
Rivers et al. (2007)

1. Not Knowledgeable 2. Moderately Knowledgeable 3. Knowledgeable

2. What type of education/training did you have to prepare you to serve those who are receiving end of life services? (select all that apply)

- Undergraduate training
- Graduate training
- Seminar/Conference
- Continuing education course
- On the job training
- No training

3. Regarding graduate course work pertaining to end-of-life/palliative care (select all that apply)

- Enrolled in an end-of-life course
- End-of-life was embedded in courses
- I have had no classes in end-of-life in my graduate curriculum

4. I received adequate training in the physical aspects of the dying process
Yes/no
5. I received adequate training in the psychosocial aspects of the dying process
Yes/no
6. I received adequate training in the cultural aspects of the dying process
Yes/no
7. I received adequate training in the spiritual aspects of the dying process
Yes/no
8. I received adequate training in ethical consideration surrounding end of life care
Yes/no

D. Palliative Care Quiz for Nursing (PCQN)

1. True or False-Palliative care is only appropriate in situations where there is evidence of a downhill trajectory or deterioration.
2. True or False-Morphine is the standard used to compare the analgesic effect of other opioids.
3. True or False-The extent of the disease determines the method of pain treatment.
4. True or False-Adjuvant therapies are important in managing page
5. True or False-It is critical for family members to remain at the bedside until death occurs

6. True or False-During the last days of life, drowsiness associated with electrolyte imbalance may decrease the need for sedation
7. True or False-Drug addiction is a major problem when morphine is used on a long-term basis for management if pain
8. True or False-Individuals who are taking opioids should also follow a bowel regime
9. True or False-The provision of palliative care requires emotional detachment.
10. True or False-During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnea.
11. True or False-Men generally reconcile their grief more quickly than women.
12. True or False-The philosophy of palliative care is compatible with that of aggressive treatment.
13. True or False-The use of placebos is appropriate in the treatment of some types of pain.
14. True or False-In high doses codeine causes more nausea and vomiting than morphine.
15. True or False-Suffering and physical pain are synonymous.
16. True or False-Demerol is not an effective analgesic for the control of chronic pain.
17. True or False-The accumulation of losses renders burnout inevitable for those who work in palliative care.
18. True or False-Manifestations of chronic pain are different from those of acute pain.

19. True or False-The loss of a distant or contentious relationship is easier to resolve than the loss of one that is close or intimate.
20. True or False-Pain threshold is lowered by fatigue or anxiety.

APPENDIX B:

Dissertation Survey

End-Of-Life Survey

For the purpose of this survey end-of-life services and/or palliative care services are used synonymously in this survey and are defined as follows: "an approach that improves the quality of life of individuals and their families facing the problems associated with life threatening illness, through prevention and relief of suffering by means of early identification and impeccably assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (World Health Organization [WHO], 2020, para. 1).

A. Demographics

1. Please indicate your gender

Female
Male
Prefer not to say
Other:

2. Please specify your ethnicity

White or Caucasian
Hispanic or Latino
Black or African American
Native American or American Indian
Asian / Pacific Islander
Prefer not to say
Other:

3. What year did you graduate with your master's degree?

1977 or before
1978-1983
1984-1989
1990-1995
1996-2001
2002-2007
2008-2013
2014-2020

4. What setting do you work in? (select all that apply)

School
Hospital
Skilled Nursing Facility
Home Health
Telepractice
Clinic
Other:

5. In your current setting(s), do you have the potential of providing therapy to an individual receiving end-of-life services?

Yes/no

B. End-of-Life Training

1. Rate your knowledge about the death and dying process
1. Not Knowledgeable 2. Moderately Knowledgeable 3. Knowledgeable

2. What type of education/training did you have to prepare you to serve those who are receiving end of life services? (select all that apply)
- Undergraduate training
- Graduate training
- Seminar/Conference
- Continuing education course
- On the job training
- No training

3. Regarding graduate course work pertaining to end-of-life/palliative care (select all that apply)
- Enrolled in an end-of-life course
- End-of-life was embedded in courses
- I have had no classes in end-of-life in my graduate curriculum

4. As a graduate student, I received competent training in the physical aspects of the dying process
Yes/no
5. As a graduate student, I received competent training in the psychosocial aspects of the dying process
Yes/no
6. As a graduate student, I received competent training in the cultural aspects of the dying process
Yes/no
7. As a graduate student, I received competent training in the spiritual aspects of the dying process
Yes/no
8. As a graduate student, I received competent training in ethical consideration surrounding end of life care
Yes/no

D. Palliative Care Quiz for Nursing (PCQN)
1. True-False-Unsure-Palliative care is only appropriate in situations where there is evidence of a downhill trajectory or deterioration.
2. True-False-Unsure-Morphine is the standard used to compare the analgesic effect of other opioids.
3. True-False-Unsure-The extent of the disease determines the method of pain treatment.
4. True-False-Unsure-Adjuvant therapies are important in managing pain

5. True or False-Unsure I am not sure-It is critical for family members to remain at the bedside until death occurs
6. True False-Unsure I am not sure-During the last days of life, drowsiness associated with electrolyte imbalance may decrease the need for sedation
7. True False-Unsure I am not sure-Drug addiction is a major problem when morphine is used on a long-term basis for management if pain
8. True False-Unsure I am not sure-Individuals who are taking opioids should also follow a bowel regime
9. True False-Unsure-The provision of palliative care requires emotional detachment.
10. True False-Unsure-During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnea.
11. True False-Unsure-Men generally reconcile their grief more quickly than women.
12. True False-Unsure-The philosophy of palliative care is compatible with that of aggressive treatment.
13. True False-Unsure The use of placebos is appropriate in the treatment of some types of pain.
14. True False-Unsure-In high doses codeine causes more nausea and vomiting than morphine.
15. True False-Unsure-Suffering and physical pain are synonymous.
16. True False-Unsure-Demerol is not an effective analgesic for the control of chronic pain.
17. True False-Unsure-The accumulation of losses renders burnout inevitable for those who work in palliative care.
18. True False-Unsure-Manifestations of chronic pain are different from those of acute pain.
19. True False-Unsure-The loss of a distant or contentious relationship is easier to resolve than the loss of one that is close or intimate.
20. True False-Unsure-Pain threshold is lowered by fatigue or anxiety.

APPENDIX C:

Original Palliative Care Quiz for Nursing (PCQN) (Original) (Ross, McDonald, & McGuinness, 1996)

Created by Margaret M. Ross, Beth McDonald, and Joan McGuinness

1. Palliative care is appropriate only in situations where there is evidence of a downhill trajectory or deterioration.

True False Don't Know

2. Morphine is the standard used to compare the analgesic effect of other opioids.

True False Don't Know

3. The extent of the disease determines the method of pain treatment

True False Don't Know

4. Adjuvant therapies are important in managing pain.

True False Don't Know

5. It is crucial for family members to remain at the bedside until death occurs.

True False Don't Know

6. During the last days of life, the drowsiness associated with electrolyte imbalance may decrease the need for sedation.

True False Don't Know

7. Drug addiction is a major problem when morphine is used on a long-term basis for the management of pain.

True False Don't Know

8. Individuals who are taking opioids should also follow a bowel regime.

True False Don't Know

9. The provision of palliative care requires emotional detachment.

True False Don't Know

10. During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment for severe dyspnea.

True False Don't Know

11. Men generally reconcile their grief more quickly than women.

True False Don't Know

12. The philosophy of palliative care is compatible with that of aggressive treatment.

True False Don't Know

13. The use of placebos is appropriate in the treatment of some types of pain.

True False Don't Know

14. In high doses, codeine causes more nausea and vomiting than morphine.

True False Don't Know

15. Suffering and physical pain are synonymous.

True False Don't Know

16. Demerol is not an effective analgesic in the control of chronic pain.

True False Don't Know

17. The accumulation of losses renders burnout inevitable for those who seek work in palliative care. True False Don't Know

18. Manifestations of chronic pain are different from those of acute pain.

True False Don't Know

19. The loss of a distant or contentious relationship is easier to resolve than the loss of one that is close or intimate.

True False Don't Know

20. The pain threshold is lowered by anxiety or fatigue.

True False Don't Know

APPENDIX D:

Description of Changes Proposed Provided to IRB

There was a misspelling of "page for pain" for question 4 on the Palliative Care Quiz for Nursing (PCQN)

Previous: True-False-Adjuvant therapies are important in managing page

Modification: True-False-Unsure-Adjuvant therapies are important in managing pain

For the PCQN addition of an additional response outside true or false of unsure. If the participant chooses unsure this will be scored as wrong. This will be beneficial due to the format of the PCQN being True or False, leading to a potential high rate of guessing correctly.

Deletion of survey questions 4 and 5 in the demographic section:

4. Please indicate your type of employment.

Responses: Part-time; Full time; Other:

5. What state did you receive your education?

Responses: Open ended

And addition of the following questions:

4. What setting do you work in? (select all that apply)

School

Hospital

Skilled Nursing Facility

Home Health

Telepractice

Clinic

Other:

5. In your current setting(s), do you have the potential of providing therapy to an individual receiving end-of-life services?

Yes/no

Modification to question #3 in the demographic section:

Original: What year did you graduate?

Modification: What year did you graduate with your master's degree?

Under B. End-of-Life Training

Modification of the following goals as follows:

4. As a graduate student, I received adequate training in the physical aspects of the dying process

Yes/no

5. As a graduate student, I received competent training in the psychosocial aspects of the dying process

Yes/no

6. As a graduate student, I received competent training in the cultural aspects of the dying process

Yes/no

7. As a graduate student, I received competent training in the spiritual aspects of the dying process

Yes/no

8. As a graduate student, I received competent training in ethical consideration surrounding end of life care

Yes/no

Implementation of revised research questions.

Original Research Questions	Modified Research Questions
Do SLPs receive training in EOL care?	Do SLPs receive training in EOL care?
If training was received, where did training in EOL care occur?	Are SLPs trained in psychosocial aspects relating to EOL care?
What training strategies relating to EOL care do SLPs find worthwhile?	Do SLPs demonstrate competent knowledge in EOL care?
What topics of dying have SLPs been trained on?	How do SLPs perceive their competence in caring for those at EOL?
	Are there differences between SLPs' perceived competence and actual knowledge in EOL care?

2. Discussion of Unanticipated Risks OR New Information

No new unanticipated risks or information that may affect the risk/benefit assessment.

3. Implications of Proposed Changes

Proposed changes are not anticipated to provide increased risk to the participants.

4. Recruitment Materials and/or consent form modifications

None.

APPENDIX E:

Protocol Exemption Report Form

VALDOSTA STATE UNIVERSITY

Institutional Review Board (IRB)
For the Protection of Human Research Participants

PROTOCOL EXEMPTION REPORT

Protocol Number: 04060-2020 **Responsible Researcher:** Tory Candea

Supervising Faculty: Dr. Katherine Lamb

Project Title: *Speech-Language Pathologists' Clinical Knowledge and Training in End-of-Life Care.*

INSTITUTIONAL REVIEW BOARD DETERMINATION:

This research protocol is **Exempt** from Institutional Review Board (IRB) oversight under Exemption **Category 2.** Your research study may begin immediately. If the nature of the research project changes such that exemption criteria may no longer apply, please consult with the IRB Administrator (irb@valdosta.edu) before continuing your research.

ADDITIONAL COMMENTS:

- *Upon completion of this research study all data (email correspondence, survey data, participant name lists, etc.) must be securely maintained (locked file cabinet, password protected computer, etc.) and accessible only by the researcher for a minimum of 3 years.*

☒ ***If this box is checked, please submit any documents you revise to the IRB Administrator at irb@valdosta.edu to ensure an updated record of your exemption.***

Elizabeth Ann Olphie *07.30.2020*
Elizabeth Ann Olphie, IRB Administrator

Thank you for submitting an IRB application.
Please direct questions to irb@valdosta.edu or 229-253-2947.

Revised: 06.02.16

APPENDIX F:

Agreement/Consent to Participate

You are being asked to participate in a survey research project entitled "Speech-Language Pathologists' Clinical Knowledge and Training in End-of-Life Care" which is being conducted by Tory Candea, a student at Valdosta State University. The purpose of the study is to add to the body of knowledge relating to preparing speech-language pathologists to competently and confidently participate in end-of-life care.

You will receive no direct benefits from participating in this research study. However, your responses may help us learn more about training in end-of-life care for the speech-language pathologist. There are no foreseeable risks involved in participating in this study other than those encountered in day-to-day life. Participation should take approximately 20 minutes to complete. This survey is anonymous. No one, including the researcher, will be able to associate your responses with your identity. Your participation is voluntary. You may choose not to take the survey, to stop responding at any time, or to skip any questions that you do not want to answer. Participants must be at least 18 years of age to participate in this study. Your completion of the survey serves as your voluntary agreement to participate in this research project and your certification that you are 18 or older. You may print a copy of this statement for your records.

Questions regarding the purpose or procedures of the research should be directed to name of responsible researcher at e-mail address. This study has been exempted from Institutional Review Board (IRB) review in accordance with Federal regulations. The IRB, a university committee established by Federal law, is responsible for protecting the rights and welfare of research participants. If you have concerns or questions about your rights as a research participant, you may contact the IRB Administrator at 229-253-2947 or irb@valdosta.edu.